DOCUMENT RESUME

ED 353 044 PS 020 816

AUTHOR Schatz, Mona Struhsaker; Mallea, Evelyn
TITLE Fetal Alcohol Syndrome: Crack and AIDS Babies. Fostering Families. A Specialized Training Program Designed for Foster Care Workers & Foster Care Parents.
INSTITUTION Colorado State Univ., Ft. Collins. Dept. of Social Work.
SPONS AGENCY Colorado State Dept. of Social Services, Boulder.
PUB DATE Apr 92
CONTRACT C-951209; UAA7T7C0000001
NOTE 72p.; For other manuals in this series, see ED 339 492-502 and PS 020 812-818.
PUB TYPE Guides - Classroom Use - Instructional Materials (For Learner) (051) -- Guides - Classroom Use - Teaching Guides (For Teacher) (052) -- Tests/Evaluation Instruments (160)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; Behavior Problems; *Cocaine; Crack; Drug Rehabilitation; *Drug Use; *Foster Care; Foster Children; *Foster Family; Infants; Medical Services; *Prenatal Influences; Symptoms (Individual Disorders)
IDENTIFIERS Colorado State University; Crack Babies; *Fetal Alcohol Syndrome; Fetal Drug Exposure

ABSTRACT

This module is part of a training program for foster parents and foster care workers offered at Colorado State University. The module examines the effects of maternal alcohol and crack use during the prenatal period on infants, and the transmission of AIDS to infants. The module's learning objectives address: (1) foster care concerns for medically fragile infants; (2) the identification of symptoms of infants who have fetal alcohol syndrome (FAS), have been exposed prenatally to drugs, or have AIDS; (3) special considerations in working with drug- or alcohol-exposed children and children with AIDS; and (4) coping skills for foster parents and foster care workers to use in working with alcohol- and drug-exposed babies. The module consists of five lectures which include reading materials, charts, and activities for individuals or groups. Lecture 1 provides an overview of the problem of prenatal drug exposure. Lectures 2 and 3 examine the characteristics of, developmental problems of, and special concerns in caring for infants who have FAS or have been prenatally exposed to cocaine. Symptoms of AIDS in babies and concerns in caring for a baby with AIDS are discussed in lecture 4. Lecture 5 suggests ways of comforting, interacting with, and caring for drug- and alcohol-exposed infants. A form for evaluating the module is appended. (BC)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

FOSTERING FAMILIES

Fetal Alcohol Syndrome: Crack and AIDS Babies

ED353044

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

X This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Mona S. Schatz

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Department of Social Work
Colorado State University
Fort Collins, CO 80523

Designed in Consultation with the Colorado Department of Social Services Under Grant Number UAA7T7C0000001

PS 020816

BEST COPY AVAILABLE

FOSTERING FAMILIES

A Specialized Training Program
Designed for
Foster Care Workers & Foster Care Parents

FETAL ALCOHOL SYNDROME

CRACK AND AIDS BABIES

Mona Struhsaker Schatz, D.S.W.
Project Director
Co-Author and Editor

Evelyn Mallea, M.S.W.
Project Research Assistant
Co-Author

April, 1992

Designed in consultation with
The Colorado Department of Social Services
Under Grant No. C 951209 & UAA7T7C0000001

Copyright pending. This material is prepared in collaboration with the Colorado Department of Social Services. All rights are reserved. No part of this manual may be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by any information storage and retrieval system without permission in writing from the project director.

FOSTERING FAMILIES

is designed to improve the competencies of caseworkers and foster care parents in the areas of foster care placement, case management and supervision, case planning, and provide an understanding of the multiple-systems interfacing with families and out-of-home children.

is a unique opportunity for foster care parents and foster care workers to explore the many complex aspects of the foster care delivery system.

is a training program designed to be comprehensive in its approach to educating those people most important to the success of foster care.

is specially designed in 3 1/2 and 4 hour sessions to meet the varying learning and educational needs of foster care providers.

is designed to foster "a partnership of skill" to effect quality care for families and children in distress.

is offered for upper-division college classwork in the Social Work Department and Division of Continuing Education at Colorado State University.

is a collaborative project with the Colorado Department of Social Services and supported with funds from Title IV-E and Colorado State University.

FOSTERING FAMILIES

ABOUT THE AUTHORS

Mona Struhsaker Schatz, D.S.W., serves as the project director for Fostering Families and Associate Professor in the Social Work Department. She received her master's in social work (M.S.W.) from the University of Denver (1979) and her doctorate from the University of Pennsylvania (1986). Since 1972, Dr. Schatz has worked in child welfare and children's services in Colorado and several other states. In the 1970's, Dr. Schatz served as a foster parent. In the 1980's she served on Greene County Missouri's Permanency Planning Committee. Since returning to Colorado, she has researched and written in the field of foster care.

Evelyn Mallea, is a research assistant and project staff member. She received her master's in social work (M.S.W.) from Colorado State University (1992). Her experience in the substance abuse field includes serving on the board of directors of an alcoholism recovery center, facilitating groups for adolescents with alcoholic relatives, and attending the summer school on Alcoholism and Other Drug Dependencies at the University of Utah.

FOSTERING FAMILIES

INTRODUCTION

Fostering Families is a specialized foster care training program. Various important learning concepts related to families, youth and children are explored *within* the context of child welfare and protective services. By paying specific attention to the foster care environment, Fostering Families' training is highly relevant for caseworkers and foster parents. Fostering Families is also unique because faculty and training staff receive regular input from foster parents and social services people who work daily to meet the needs of children in out-of-home placement. Thus, this training project continues to evolve because of the on-going training program.

Our goal is to create small group training experiences which offer new knowledge, concepts, ideas, and skills to improve (1) the foster care assessment and placement process, (2) the case planning, monitoring and supervising process, and, (3) the recruitment and retention of foster homes.

Foster parents and caseworkers are learning collaboratively in each session. Each module is designed to motivate participants to go beyond simple transmission of information to training opportunities created so that trainees can apply concepts either in role play situations, small group experiences, or through individual activities. Participants are also provided the opportunity in the training session to integrate their learning through discussion and group experiences. To achieve high accessibility for foster parents, training sessions are often held in the evenings and on weekends. To afford access to caseworkers, sessions are also scheduled on weekdays. Each week training sessions are held throughout the urban, suburban and rural areas of the State.

Because of the growing number of medically fragile babies in out-of-home care, this module, Fetal Alcohol Syndrome, Crack, and AIDS Babies, examines the bases of each concern. Through this training, we hope to improve the foster care assessment and placement process by providing information about the care needs of children who have been exposed prenatally to alcohol, drugs, and/or AIDS. Particular issues arise for protective services and foster care, particularly because of the specialized home care these children need.

Specific suggestions are given about how caseworkers and caregivers can identify problem areas and assist these types of children. Referral services and varying types of supports available to foster parents are outlined.

FOSTERING FAMILIES

INTRODUCTION

Each manual is written to provide a wide range of information on the topic area being addressed. In the training session it is unlikely that everything in the manual is equally addressed. We recommend that the manual be read completely soon after a training session. We have been told that this helps greatly toward gaining a full understanding of the issue at hand.

Colorado State University allows participants the opportunity to gain university credit when a series of training sessions are satisfactorily completed. During the session, the training instructor will review procedures for applying for credit.

We welcome you to this Fostering Families training session. We encourage you to participate fully in the training; ask questions that help you (and others) in this interesting and challenging learning opportunity.

FOSTERING FAMILIES

TABLE OF CONTENTS

Page

Introduction i

Table of Contents iii

Glossary of Terms 1

Learning Objectives 2

Lecturette #1: Introduction: The Drug Exposed Infant 3
Chart A: Effects of Prenatal Drug Exposure 7

Lecturette #2: Fetal Alcohol Syndrome 9
Chart B: Major Identifying Characteristics 10
Chart C: Facial Features in Fetal Alcohol Syndrome 11
Chart D: Techniques for Caring for FAS Infants 14

Lecturette #3: Cocaine And Crack Babies 19
Box A: Care For Susie 26
Exercise #1: Practice Dilemma 28

Lecturette #4: Infants with AIDS 29
Exercise #2: Caring for Infants with HIV 32
Chart E: Precautions in Caring for Infants with AIDS 34
Chart F: Care Needs of HIV-Affected Children 36
Vignette: A Story of Love 38

Lecturette #5: Caring For Medically Fragile Infants 44
Chart G: Comforting Drug Exposed Infants 46
Chart H: Techniques for Drug/Alcohol Exposed Infant 47

Exercise #3: Practice Situation AIDS Infant 51

Exercise #4: Homework Assignment 52

Key Points 53

Suggested Resources 54

Application for Partial Credit 57

Evaluation of Learning 58

FOSTERING FAMILIES

GLOSSARY OF KEY TERMS

cocaine/crack babies	**Babies whose mothers used cocaine/crack during pregnancy. Cocaine and crack (a form of cocaine that is smoked) are stimulants that affect the central nervous system. When a baby is exposed in utero, he/she is at risk for premature birth, birth defects, and central nervous system damage.**
drug exposed baby	**A broader term than alcohol or crack baby, used to connote the multiple drug use behavior of pregnant mothers that then affects the baby.**
Fetal Alcohol Effects (FAE)	**Having some of the characteristics of Fetal Alcohol Syndrome but not enough for a full diagnosis. Such a child may be hyperactive, learning disabled, or have other not so obvious abnormalities caused by maternal alcohol intake during pregnancy. FAE is often not diagnosed.**
Fetal Alcohol Syndrome (FAS)	**A pattern of physical, cognitive, developmental, and behavioral abnormalities present in some children whose mothers drank alcohol heavily during pregnancy.**
Human Immunodeficiency Virus (HIV)	**A virus that attacks the body's immune system, undermines its ability to ward off infections and diseases, and results in AIDS.**
Acquired Immune Deficiency Syndrome (AIDS)	**A severe infection of the immune system caused by the (HIV) Human Immunodeficiency Virus which results in an acquired defect in immune functioning. It reduces the infected person's resistance to infections and disease. AIDS is the end stage of infection with HIV and has no known cure.**
in utero	**This term refers to being in the uterus. A baby is in utero prior to birth.**
medically fragile infant	**Refers to babies born with serious medical problems including AIDS babies and seriously drug-exposed babies.**

FOSTERING FAMILIES

LEARNING OBJECTIVES

1. Through discussion and presentation of materials, participants will be able to identify the difficult foster care concerns for medically fragile infants who have been prenatally exposed to and affected by alcohol and/or drugs or may be suffering from AIDS. This will enhance the out-of-home placement, assessment, and ongoing case-monitoring processes.

2. To improve the case planning and placement process, participants will learn to identify some of the signs, symptoms, and behaviors of children who have fetal alcohol syndrome or fetal alcohol effects, who have been exposed prenatally to drugs, or who have AIDS.

3. To enhance the caregiving in the placement process, trainees will examine important components of working with these children such as assisting them with attaching behaviors, helping to calm them down when overstimulated, and providing a relatively tranquil environment.

4. To improve case supervision and management, workers and foster parents will learn personal coping skills to work with these special need alcohol/drug exposed babies.

FOSTERING FAMILIES

INTRODUCTION: THE DRUG EXPOSED INFANT

Lecturette #1

A dramatic increase in substance abuse by women in their child-bearing years is leading to large numbers of medically fragile infants being born each year. These babies have drug withdrawal symptoms, multiple physical problems, mental retardation, developmental delays, learning disabilities, behavioral problems, or AIDS. Making this situation even more difficult, is the reality of a large proportion of these infants entering the foster care system. Child protective workers and foster parents need to be knowledgeable of the special needs and care requirements of these young children.

This module will discuss many of those special needs, the care requirements, foster and social service issues, and parenting concerns surrounding crack babies,children with Fetal Alcohol Syndrome (FAS), and AIDS babies. In this training program, we will also provide an overview of the potential and real physical and medical problems for these children. In preparing this material, we sought out the most current material on these disabled babies in print. We contacted experts and professionals who could help in our understanding of these issues. We want each reader and trainer to recognize that we do not represent the medical community in the conclusions presented here. Further, we are very aware that medical research is helping improve the circumstances of these babies and thus, this material may become outdated rather quickly. In the "Suggested Resources" section of this manual, we provide specific referral and information organizations to provide updated information as you may need it.

ESTIMATING THE EXTENT OF THE PROBLEM

Reports vary greatly on the number of drug and/or alcohol exposed infants. Estimates of babies exposed prenatally to illegal drugs range from one to eleven percent of all babies born in the United States each year or in other words, 40,000 to 375,000 babies (Besharov, 1991; Chasnoff, 1988). Estimates for babies born with Fetal Alcohol Syndrome vary from one in every 750 births to two in every 1000 births (May, 1986; Abel, 1987). The prevalence of *Fetal Alcohol Effect* is thought to be about twice as high as *Fetal Alcohol Syndrome*.

These report variations mirror the difficulty in assessing the extent of the problem. A common problem is the reluctance of mothers to report their use of drugs or alcohol. In some instances, infants do not show signs of drug exposure at birth. The severity of prenatal damage from drug and alcohol should be understood by thinking of a continuum with "no effects" on one end to "severe" Fetal Alcohol Syndrome or multiple physical effects leading to death on the other end. What lies in between are the varying degrees of impairment, often not diagnosed as connected with prenatal drug and/or alcohol use, but rather, as later diagnosed learning disabled, behavioral problems, or hyperactivity in a child's latency years (5-13).

Why some infants are severely affected through drug exposure and others are not cannot be readily explained. According to Dr. Dan Griffith (1988), a developmental psychologist at the Perinatal Center for Chemical Dependence in Chicago, it is unknown how much cocaine or alcohol is needed to cause damage to a developing fetus. Since cocaine and alcohol affect individuals in varying ways, it is hard

to tell how extensively an infant of a user is affected. *The riskiest time for use is during the first three months of pregnancy when the nervous system and body organs are forming.* However, even a single dose of cocaine at any time during the pregnancy can cause brain damage in the fetus. Unfortunately, women who use cocaine or alcohol during their pregnancies often use other drugs or smoke cigarettes which also increase the risks to the developing fetus. For this reason, many experts do not use the term "crack baby" but rather "drug-exposed" when describing for these babies.

COMMON CHARACTERISTICS OF DRUG AND/OR ALCOHOL EXPOSED INFANTS

Whatever the drug or combination of drugs used by the mother, the developing fetus of a substance abusing mother has an increased chance of dying in utero, being born prematurely, having multiple physical abnormalities, having a low birth weight, and having withdrawal symptoms.

Withdrawal symptoms occur because the fetus can develop a dependency to alcohol and/or drug/drugs while in utero. When he/she is no longer exposed to the substance at birth, withdrawal symptoms will occur. The severity and onset of withdrawal symptoms depend on the substance used by the mother, the amount and frequency of use, and when the mother last used drugs prior to delivery.

FOSTERING FAMILIES

Lecturette #1 (Cont'd)

Symptoms usually start a few hours after birth, but may not peak for three or four days, and can last for two or three weeks (Chasnoff, 1988). The most common symptoms are:

- ***irritability**
- ***high-pitched cry**
- ***poor feeding**
- ***gastrointestinal upset (vomiting/diarrhea)**
- ***hyperactive reflexes**
- ***restlessness**
- ***tremors**
- ***oversensitive skin**

It is often difficult to determine if an infant is having withdrawal symptoms or symptoms of the effects of drugs and/or alcohol on their central nervous system. Because the central nervous system is affected by drugs/alcohol, these infants tend to be irritable, cry persistently, are hard to console, can be easily disturbed, are resistant to touch, and have difficulty interacting with their caretakers. Because of these factors, caring for and bonding with these babies may be difficult.

GROWING NUMBERS IN FOSTER CARE

These medically fragile infants are the fastest growing population in foster care. **Many of these infants are born into economically disadvantaged families, are often born prematurely and require prolonged hospitalization, and are sometimes abandoned by mothers in the hospital.**

Individual or Group Activity:

Examine Chart A - "Effects of Prenatal Drug Exposure."

FOSTERING FAMILIES

EFFECTS OF PRENATAL DRUG EXPOSURE

Chart A

EFFECTS OF PRENATAL DRUG EXPOSURE

	CNS DEPRESSANTS: ALCOHOL	NARCOTICS	BARBITURATES	TRANQUILIZERS	MARIJUANA	CNS STIMULANTS: COCAINE(CRACK) AMPHETAMINES
POOR BODY GROWTH (S.G.A.)	X	X			X	S
POOR BRAIN GROWTH	S	X			X	S
WITHDRAWAL SYNDROME	X	S	X	X	X	
STIMULANT SYMPTOMS						X
CHRONIC FEEDING PROBLEMS & IRRITABILITY	X	X	X	X	X	X
ABNORMAL NEURO-BEHAVIORAL RESPONSES	X	X	X	X	X	X
ABNORMAL PARENT-INFANT INTERACTIONS	X	X	X	X	X	X
BIRTH DEFECTS	X	X				X
ABNORMAL FACIAL FEATURES	X				X	
DEVELOPMENTAL DELAYS	X	X	X		X	X
LOWER I.Q.	X	X	X			
BEHAVIORAL PROBLEMS, ATTENTION DEFICIT	X	X	X			X
LEARNING DISABILITIES	X	X	X			X
SIDS		X				X

X = Associated & Related
S = Can be very severe

From: Langendoerfer, S. (June, 1990). Results of a working conference on the community response to drug exposed infants. Denver, CO.

*CNS Depressants: Drugs that depress or slow down the central nervous system (brain & spinal cord). Immediate effects include sedation and a decrease in bodily functions. These drugs can act as mood elevators by lowering inhibitions. High doses can lead to sleep, coma, & death. If alcohol & another depressant are taken together, they compound the effects of each other and greatly increase the risk of death.

**CNS Stimulants: Drugs that excite the central nervous system and produce an elevation of mood, a state of wakefulness, and increased mental activity and energy. These drugs cause a racing heart and increased blood pressure and pulse rate. Irritability and fatigue set in after a stimulant wears off, and users can eventually feel depressed.

FOSTERING FAMILIES

Lecturette #1 (Cont'd)

Fifty percent (50%) of these infants do go home with their mothers, often to a substance abusing environment which puts the infants at high risk for neglect and abuse. Child protection services (CPS) intervenes in cases of abandonment of these children. In some states, CPS intervenes if an infant tests positive for drugs, alcohol, or AIDS. Due to the overload in the foster care system, these babies are sometimes kept for months in a hospital, even though it's not medically necessary, awaiting an appropriate foster home. These "boarder babies" as they are referred to, are at risk of poor bonding and attachment, thus facing more difficult problems in their growth and development.

Because of these multiple factors, it is estimated that eighty percent (80%) of identified drug or alcohol exposed infants will enter foster care within their first year of life (McCullough, 1991). From June, 1987 to June, 1990, foster care placements in the United States increased by 29% with the majority of the increase being from these drug/alcohol exposed infants and children being channelled into the system.

FOSTERING FAMILIES

FETAL ALCOHOL SYNDROME

Lecturette #2

Fetal Alcohol Syndrome (FAS) is a pattern of physical, cognitive, developmental, and behavioral abnormalities present in some children whose mothers drank alcohol heavily during pregnancy. Since the syndrome was named in 1973, over 550 cases have been described in the scientific literature (Abel, 1990).

FAS is now recognized as the leading known cause of mental retardation in the United States (Abel, 1987). The major characteristics of FAS are prenatal and/or postnatal growth retardation, developmental delays, mild to moderate mental retardation, behavioral disorders, small head circumference, and characteristic facial features (See Charts B & C for details). In addition, FAS children frequently have physical abnormalities such as a cleft palate, heart defects, vision and hearing deficiencies, skeletal defects, and teeth deformities (Abel, 1990).

Children affected prenatally by alcohol can be described on a continuum from minor effects on one end to severe Fetal Alcohol Syndrome on the other. Those with mild to moderate effects usually have one or two of the major characteristics of FAS but are said to have Fetal Alcohol Effects (FAE) rather than FAS. The number of infants with FAE is thought to be twice as high as those with FAS (Streissguth, et al, 1988). Unfortunately, those with mild Fetal Alcohol Effects are often not detected and are otherwise labelled as learning disabled, hyperactive, or attention deficit disordered.

<u>Individual or Group Activity</u>:

See Chart B describing the major characteristics of FAS.

Examine Chart C entitled, "Facial Features in Fetal Alcohol Syndrome."

FOSTERING FAMILIES

MAJOR IDENTIFYING CHARACTERISTICS OF FETAL ALCOHOL SYNDROME

Chart B

Mild to moderate mental retardation - average IQ 70

Extremely small size for age

Unique Facial features (See Chart C)

Hyperactivity

Distractibility

Poor fine-motor ability

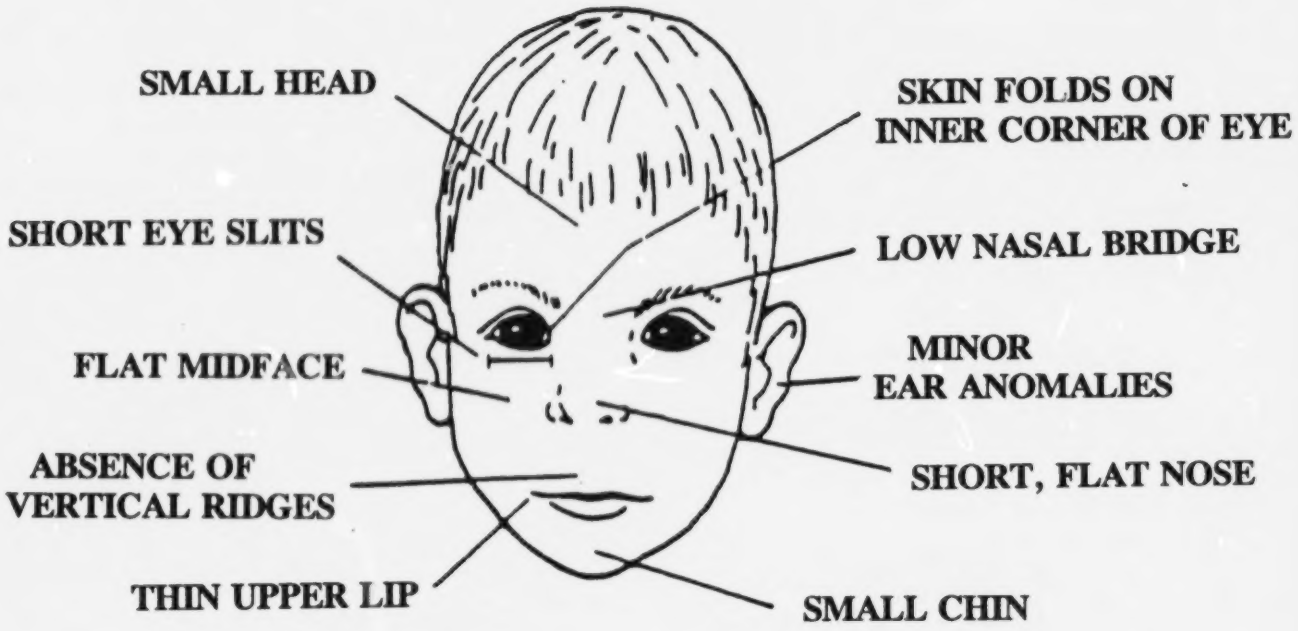
Speech and language defects

Small body size

FOSTERING FAMILIES

FACIAL FEATURES IN FETAL ALCOHOL SYNDROME

Chart C



EARLY PHYSICAL AND BEHAVIORAL CHARACTERISTICS

Withdrawal

FAS babies can have varying degrees of alcohol withdrawal, depending on the severity of the mother's drinking. Onset of symptoms usually occurs within the first 12 hours after birth and can be much less obtrusive and relatively milder in comparison to narcotic withdrawal (Abel 1990). Symptoms include tremors, irritability, increased muscle tone, arching of back, abdominal distension, vomiting, seizures, abnormal breathing patterns, heightened sensitivity to sound, excessive sucking actions, hyperactive rooting, and excessive hand-to-mouth behaviors (Pierog, et al, 1977; Coles, et al, 1984). Alcohol withdrawal symptoms usually subside within a week; however, if the mother abused other drugs in addition to alcohol, the infant may experience symptoms longer and more severely.

Physical and Behavioral Disorders

FAS infants are small when born, usually in the lower tenth percentile and weigh on the average from four to five pounds even as full-term babies (Abel, 1990). FAS infants and children remain small. They remain below the third percentile for height, weight, and head circumference as they grow.

Feeding problems are common because of weak sucking and a tendency to tire easily. These infants have minimal weight gain regardless of food intake and are frequently diagnosed as failure to thrive. Unfortunately, little can be done to enhance their growth.

Group Activity:

View segments of video discussing FAS.

FOSTERING FAMILIES

Lecturette #2 (Cont'd)

During the first six months of life, FAS babies tend to be irritable, cry a lot, are resistent to touch, and have heightened sensitivity to sound. Sleeping difficulties are common. These infants are awake more than nonaffected babies, have difficulty falling asleep and reaching quiet sleep. FAS babies are easily aroused from sleep by external stimuli and move a lot during sleep (Abel, 1990).

In addition, these babies are highly susceptible to a number of medical problems. The most frequent is ear and respiratory infections that can be severe. Some babies have seizures that require medication for control. Others have heart defects, skeletal deformities, and, hearing and visual disorders that require on-going medical attention. Other, less frequent medical problems include cleft palates, urinary tract defects that cause frequent urinary tract infections, liver dysfunction, and malignant tumors (Rosett & Wagner, 1984).

Caring for FAS Infants

Because of the physical and behavioral problems of these infants, the caretaker is in a demanding care-taking situation. Dealing with an irritable and hard to console baby is in itself difficult; however, caring for a FAS baby can multiply the stress for the caregiver because of the added problems with feeding, sleeping, and medical conditions. This puts FAS infants at increased risk for neglect and abuse especially when in an impoverished and/or substance abusing environment.

Chart D provides some recommended techniques for caring for FAS babies. Improving the feeding, sleeping, and irritability for these children requires structured regular care-taking responses. Medical concerns requires a strong doctor and parent relationship.

Individual or Group Activity:

Examine Chart D entitled, "Techniques for Caring for FAS Babies."

FOSTERING FAMILIES

TECHNIQUES FOR CARING FOR FETAL ALCOHOL SYNDROME BABIES

Chart D

FEEDING PROBLEMS

Feed small amounts frequently. Allow extra time for feedings. Limit distractions during feeding.

SLEEPING PROBLEMS

Have a quiet and dark sleeping area for the baby. Keep external noise to a minimum; swaddle baby when he/she is having difficulty sleeping. Make eye contact and use a soothing voice when interacting with baby.

IRRITABILITY AND PROLONGED CRYING

Be aware of and respond to early cues that infant is becoming distressed (yawns, increased movement, color changes, frowns, and eye aversions) to avoid baby reaching a frantic cry state. Swaddle baby with a blanket, hold snugly and closely, use a pacifier, and rock in a vertical position.

MEDICAL PROBLEMS

Develop a good relationship with the pediatrician and other medical personnel that are involved in the baby's care. Ask questions about the baby's medical and physical problems and the care for those problems. Familiarize yourself with medical terminology. Be prepared to spend a good deal of time in doctors' offices, hospitals, etc., as it's not unusual for FAS infants to be readmitted to the hospital for failure to thrive, pneumonia, or evaluation of other medical problems.

LONG TERM DEVELOPMENTAL AND BEHAVIORAL DISORDERS OF FAS-AFFECTED

Toddler and Preschool Years

During the toddler and preschool years, Fetal Alcohol Syndrome children are slow to walk, to be toilet trained, and to talk. They often have poor fine and gross motor control and poor coordination which contribute to delayed walking. Talking is often delayed until around age three, but once talking starts, they talk a lot and ask a lot of questions. However, they are slow to combine words, have problems with articulation, lack fluency of speech, and are hard to understand (Rosett & Weiner, 1984).

FAS children also tend to be hyperactive, to be very restless, to have short attention spans, to be easily distracted, and to rock their heads and bodies. They have difficulty sitting still even for a minute, and have a tendency to wander away. They have difficulty learning from past experience. They are often extremely outgoing and friendly, to the point of being annoying. They are not afraid of strangers and seem to have an insatiable need for bodily contact. Because of these factors, they need closer than usual supervision.

During this period, these children are usually short and elf-like in manner and appearance and have a happy disposition (Streissguth, et al, 1988). Because of these qualities, many people find FAS children endearing during this time and often do not take seriously their slow and poor development.

Physically, this age group of FAS children continue to grow slowly, are very small for their age, have poor appetites, and have sleeping problems. Medical problems persist, particularly frequent are severe ear infections and susceptibility to childhood diseases.

School Age Behavioral Disorders

By school age, these youth continue to be hyperactive, have short attention and memory spans, are easily distracted, and cannot concentrate on a single task for very long. Because of the short memory spans, they may have to be continually reminded to eat, dress, go to the bathroom, and bathe.

Social adaptation is particularly difficult for FAS children. Even though they are outgoing and socially engaging, they are frequently seen as intrusive, overly talkative, and generally unaware of social cues and conventions. Poor social judgement and poor socialization skills are common. They have difficulty comprehending social situations, remembering appropriate behavior, and knowing when to say "no" (Streussguth, 1988). They tend to be very naive, easily persuaded, and are prime targets for sexual abuse. They have difficulty making friends with other children and may become socially withdrawn. As they grow older, their behavior may become more impulsive. They may show a lack of consideration for others. They may lie, cheat, or steal without comprehending the consequences of their actions (Streissguth, et al, 1991).

FOSTERING FAMILIES

In addition, FAS children often have learning disabilities and special educational needs, requiring placement in special education classes. In a regular classroom setting, these children's short attention span and distractibility may compound their ability to learn. They learn best in a one-on-one or small group situation with minimal distractions. Arithmetic deficits are the most common learning disabilities of these children, and as a result, they may never learn to tell time or make change. They can learn to read and write, often better than their IQ scores would predict; however, comprehension of what they read is low (Smith, 1989).

FOSTER PARENTING NEEDS

The combination of physical, intellectual, and behavioral problems of FAS children can create a very demanding situation that goes far beyond the normal responsibilities of parenting. These children often require close supervision and highly structured family environments. Parenting includes regular reminders of daily living and safety routines. This takes an extraordinary amount of time, energy, love, and consistency (Streissguth, 1988).

In order to deal with these demands, workers and foster parents need general information about Fetal Alcohol Syndrome and specific information related to the child in care. It is important to understand the child's physical and behavioral limitations in order to develop realistic expectations and to plan appropriate care for the child.

FOSTERING FAMILIES

In addition, foster parents need strong support systems and good self-care practices while caring for FAS children. A support group for caretakers of FAS children is ideal, however, that may not be available. Other options would be a support group for parents of handicapped children or a support system with other foster parents who are caring for or have cared for FAS children. Also, foster parents need a strong and supportive relationship with social service workers. Workers need to be knowledgeable about FAS and serve as advocates in securing the necessary financial, medical, and educational assistance needed by these children.

Most important, foster parents need to take care of themselves emotionally and physically. Respite care is a must. Having time away from the 24-hour daily stress and demands of these children is essential for your own well being.

CONCLUSION

A Fetal Alcohol Syndrome child needs love and nurturing in a supportive environment as does any other child. Even though they require a great deal of care, these children can thrive in a loving family that provides good structured family life, strong communication, patterns, and supportive medical care.

FOSTERING FAMILIES

COCAINE AND CRACK BABIES

Lecturette #3

Cocaine abuse has increased in the last decade with an estimated 20 million Americans having used this drug. This increase is attributed to the emergence of crack which is a form of cocaine that is smoked. Crack produces an immediate high, is highly addictive, and is becoming extremely popular in the lower socio-economic population. Unfortunately, the increased use of cocaine/crack also includes pregnant women. Since 1985, hospitals in major cities report a marked increase of drug exposed infants being born, three to four times as many for some hospitals (Miller, 1989).

This high number of drug exposed infants is a problem because these babies are often born prematurely, are small in size even if full term, have developmental and behavioral problems, are sometimes physically deformed, and are at risk for AIDS. This is a story similar to FAS. Risk of becoming HIV is a sharp deviation, however. Often extended hospitalization is required for these drug-exposed babies. It is not uncommon for these babies to be abandoned by the mother or to be placed under the supervision and control of the child welfare system.

Though we have had drug-exposed babies for many decades, the higher potency of drugs today creates problems that physicians and surgeons are only becoming aware of day by day. Much research is underway.

Withdrawal

Since studies on cocaine exposed babies are fairly new, the presence, severity, and length of withdrawal symptoms are not fully documented. Chasnoff (1988) says that cocaine/crack newborns are irritable, cry a lot, have tremors, are restless, have rigidity of muscles, and, have poor feeding and sleeping behavior (which are generally signs of withdrawal).

However, it has not yet been determined if these symptoms are from withdrawal or from the effects of cocaine on the central nervous system.

If a mother uses cocaine within a few days of delivery, cocaine is still present in the infant's system, affecting the central nervous system of the baby, causing hyperactivity and increased heart and respiratory rates. A baby can be born still suffering from the effects of the mother's last use of cocaine. In addition, the mother often is abusing alcohol, cigarettes, and other drugs that can add to the baby's symptoms.

EARLY PHYSICAL AND BEHAVIORAL CHARACTERISTICS

Physical and Behavioral Disorders

Cocaine/crack babies are often born prematurely and may have a low birth weight even if full term. These infants often remain small for their age which may be partly due to feeding problems as newborns. They often have poor control of the sucking process, are hypersensitive around the mouth, and have problems being calmed enough to feed.

Healthy, non-drug exposed newborns normally cycle through regular periods of sleep, being awake, and crying. Infants usually spend some time in each state, move smoothly from state to state, and as they grow, spend more time in quiet alert states and less time sleeping and crying. Cocaine/crack babies do not show these organized behavioral states or the smooth transitions from crying to awaken states, but rather go rapidly from one extreme state to another such as going from deep sleep to frantic crying (Schneider, Griffith, & Chasnoff, 1989).

Attaching to a primary caregiver is critical for normal infant development. The drug-exposed baby challenges the caregiver in this process. For example, when the cocaine/crack infant is exposed to stimulation, they either remain in deep sleep, do not respond to handling, or become stressed and frantic, making interaction with them very difficult. They avoid making eye contact, have a high pitched cry, cry for long periods of time, and often will cry more intensely if handled or stimulated in any way. Because of their inability to interact with the caregiver in a normal way, bonding with these infants is very difficult.

These infants do not have the same flexibility in their limbs as normal infants. When lying down, cocaine/crack babies often lie in excessively extended postures. Movements of their extremities may be jerky and stiff. When they are held in an upright position, they have stiff extension of hips, knees, and ankles and bear weight on their toes. Tremors are evident when they reach out for objects, and stiffness in their legs prevents them from exploring their lower body (Schneider, Griffith, & Chasnoff, 1989).

As a consequence of this body stiffness, these babies are hard to hold. Their motor development activities such as sitting up, crawling, and reaching for objects will be delayed. Physical therapy may be required to help with the stiffness.

These infants are also at risk for genital and urinary track abnormalities, strokes, seizures, and Sudden Infant Death Syndrome. They are also at high risk for AIDS because mothers using cocaine are also prone to be intravenous drug users or have partners who use intravenous drugs.

CARING FOR COCAINE/CRACK BABIES

Because of their irritability, poor state control, and inability to interact with the caregiver, caring for cocaine/crack babies can be extremely challenging, putting them at high risk for abuse and neglect especially if living in a substance abusing environment. These infants require an extraordinary amount of time and patience. The best environment is probably a low key, low stimulus environment.

Initially the infant may respond best to swaddling and slow vertical rocking to be calmed. Using a pacifier while rocking also may help. It is recommended that the caregiver limit stimulation as cocaine/crack babies are easily overloaded by stimulation. For example, it may be best to rock the baby without talking or singing to him/her simultaneously.

Chose a time when the baby is calm to work at bonding. Hold the baby vertically, facing you, and gently rock up and down. The baby often will respond by opening his/her eyes and looking at you. At first the eye contact may be brief, and it's best

to at first avoid talking when the baby makes eye contact. If the baby starts to sneeze, yawn, cough, stiffen, or thrash around, stop the interaction and allow him/her to rest. As time goes on, the baby will be able to tolerate interaction for longer periods of time (Griffith, 1988).

Cocaine/crack babies also need special attention given to their stiff muscle tone. Avoid laying the baby on his/her back for prolonged periods. Vary the baby's position often, exercise his/her legs and arms to relax the muscles, and when holding him/her, bend up the baby's legs and bring his/her arms around. Carry the baby in a flexed position with the infant sitting on your hip and supported by your arm under his/her thighs (Schneider, Griffith, & Chasnoff, 1989). Also, bathing the baby frequently in warm water may help. It is recommended that parents not use walkers and jumpers as their use encourages the stiff extension of these infants' legs and posture.

LONG TERM DEVELOPMENTAL AND BEHAVIORAL PATTERNS

Cocaine/crack children are now just reaching school age and little is known as to what happens from here. One thing is known, however, that regardless of their age, these children require a structured environment and patient, one-on-one attention from caregivers for maximum functioning.

As toddlers and preschoolers, we recognize that these cocaine/crack children tend to be irritable, display poor impulse control, have delays in speech and language, and are poor at problem solving. They are less securely attached. They also easily distracted, become easily frustrated, and have

problems in organizing play. They show extremes in behavior ranging from apathy to aggression, passivity to hyperactivity, and indiscriminate trust to extreme fear and suspicion (Cole, 1988). These children also have more problems with an unstructured environment and can easily reach a frantic state.

Whether these behaviors are just from being exposed to cocaine prenatally or from a combination of drug exposure and living in a substance abuse environment is yet to be determined.

FOSTER PARENTING NEEDS

Because of the irritable temperament and medical care needs of these babies, foster parents are subjected to a demanding situation that requires an extraordinary amount of patience, time, energy, and love. In order to deal with these demands, workers and foster parents need current, accurate information about cocaine/crack babies so that they can see realistic expectations for treatment and plan appropriate care for the child and family.

In addition, foster parents need support while caring for these infants. A strong family and social support system help immensely to relieve the day to day stresses. A support group of foster parents particularly including parents who are caring for or who have cared for drug babies would be ideal. A strong and supportive relationship with social service workers is needed to secure the financial and medical help needed for these children.

Individual or Group Activity:

Look at Box A - "Foster Family Describes Care for Susie."

FOSTERING FAMILIES

Lecturette #3 (Cont'd)

Most importantly, foster parents need to take care of themselves emotionally and physically while caring for these infants. Frequent time away is essential for your well being. Also, being aware of feelings such as inadequacy or anger that may surface and processing those feelings with someone can add to you well being. To relieve some of the stress while caring for a cocaine/crack baby, it may be necessary to limit the number of foster children in your home.

It's important to remember that these infants' irritability and problems with interaction have nothing to do with your parenting skills. Being patient and giving them love and nurturing as you would any other child is the best thing you can do.

<u>Individual or Group Activity</u>:

Review Exercise #1.

FOSTERING FAMILIES

FOSTER FAMILY DESCRIBES CARE FOR SUSIE
Box A

Keri & George Smith became foster parents to Susie when she was dismissed from the hospital at 3 weeks of age. Susie's birth mother abused cocaine, heroine, and alcohol while she was pregnant with Susie. As a result, Susie has multiple medical problems.

We interviewed the current foster parents about their caring for Susie. The daily efforts to help Susie grow strong are quite enormous, and demonstrate the great strength, flexibility, and caring from a foster family. Keri says they have not had any social life since caring for Susie. However, they have become very emotionally committed to Susie and plan to adopt her.

Keri and George do not use much respite care time because of the critical medical issues. They did however, recruit and train four volunteers (from their church and the hospital) to help. The foster parents recount the challenge for volunteers when they told this story: One day a volunteer stayed with Susie. Susie had a seizure and stopped breathing. An ambulance was called and Susie had to be hospitalized. This scared off the volunteer, she will not return.

Keri talked quite a bit about how busy every day is for her. Caring for Susie is a 24-hour a day job. She said she feels bad for the other four children (ages 4 through 16) in the family right now, but the children accept Susie as their new baby sister and do what they can to help. Keri described some of the regular activities connected to Susie's care. They are summarized below.

<u>DAILY CARE ROUTINE</u>

- **Routine infant care including feeding, bathing, and diapering - feeding, however, takes an extra length of time**
- **Nebulizer treatment every four hours around the clock for 15 minutes followed by CPT for 30 minutes that keeps fluid out of Susie's chest**
- **Medications given every four hours around the clock**
- **Twice a day, Susie requires hydrotherapy for 30-45 minutes for the hypertonicity of muscles**

Box A (Cont'd)

* **Watch oxygen and heart monitor, make sure tape on oxygen tube stays taped to Susie's face**

* **If she stops breathing, stimulate her by gently shaking**

* **Nurse's aide comes for 2 hours per day Monday through Friday - 8:00 a.m. to 10:00 a.m. or 4:00 p.m. to 6:00 p.m. to give Keri some time to do things like take a shower or cook dinner**

WEEKLY CARE REQUIREMENTS

* **Nurse comes to home weekly**

* **Weekly respiratory therapist - comes on Tuesdays**

* **Every other Thursday, someone from Infant Stim Program comes to do physical therapy on Susie for one and one-half hours**

OUT OF HOME CARE

* **Susie has had an average of one hospitalization a month since initial dismissal from hospital**

* **Physicians seen include:**
  Pediatrician once a week
  Neurologist every two weeks
  Gastrointrologist every six weeks
  Neonatologist
  Opthomologist
  Cardiologist
  Genetics Clinic for Children

* **Occupational therapist every other week at hospital**

FOSTERING FAMILIES

PRACTICE DILEMMA:
Exercise #1

Sarah Essex, a foster parent, has been caring for Jennifer Jones since she was discharged from the hospital four months ago. Jennifer spent the first two months of her life in the hospital because she was born prematurely and had been exposed to crack and alcohol in utero. When Sarah first brought Jennifer home, she was irritable, startled easily, and was hard to console. She also required much medical attention because of her exposure to crack and alcohol. Sarah spent many hours caring for Jennifer and taking her to medical appointments.

Along with the time required for physical and medical care, Sarah spent much time working at bonding with Jennifer. Jennifer is now much quieter and appears to have bonded with Sarah. Sarah has become quite attached to Jennifer.

Last week Jennifer's mother, Susan Jones, called and wanted to see Jennifer. Sarah reluctantly agreed and arranged a time for her to visit. Susan arrived with alcohol on her breath and her pupils were dilated. Upon seeing Susan's apparent intoxicated condition, Sarah refused to let her in. Susan consequently started swearing and yelling, and Sarah threatened to call the police. Susan then left.

Break into small groups. Discuss the following questions related to the story above.

1. **Discuss the visitation issues that exist in this situation. How should the worker respond?**
2. **Do you think Sarah did the right thing by refusing to let Susan see the baby?**
3. **What would you have done in a situation like this?**
4. **How do you think the foster mother feels about the birth mother?**
5. **How would you feel if you were in Sarah's place?**

FOSTERING FAMILIES

INFANTS WITH AIDS

Lecturette #4

The increase of drug abuse by pregnant women not only has created a population of children who have developmental, physical, and behavioral problems but it also has introduced Acquired Immune Deficiency Syndrome (AIDS) into the infant population. Women who abuse any form of drugs are at high risk for contacting AIDS because of intravenous(IV) drug use or having a partner who is an IV drug user. If a woman becomes pregnant after being infected with the virus, there is a 50 percent chance the baby will be positive for Human Immunodeficiency Virus (HIV) at birth and later develop AIDS (Rogers, 1987).

If exposed prenatally to HIV, a baby is not born with AIDS but rather with the AIDS antibody from the mother which can cause the baby to be HIV positive. It is believed that seventy percent (70%) of infants who are HIV positive at birth will not develop AIDS; however, their actual HIV status cannot be determined until all the mother's antibodies are gone from the infant's bloodstream which happens at around 15-24 months of age. Fifty percent (50%) of the infants who are infected will develop symptoms of HIV infection by six months of age and will be diagnosed with AIDS by 12 months (Sokal & Ramler, 1991).

If a baby is HIV positive and develops symptoms, he/she has been infected with the Human Immunodeficiency Virus which can harm the body's immune defenses and affect other body systems. A baby is not diagnosed with AIDS until he/she develops a certain combination of illnesses associated with HIV.

SYMPTOMS OF HIV/AIDS IN INFANTS

Symptoms in infants with HIV/AIDS are failure to thrive, weight loss, swollen glands, recurrent bacterial infections, persistent thrush (fungus infection of the mouth, nose, and throat), chronic or recurrent diarrhea, and persistent or recurrent fever. As the disease progresses, an opportunistic infection such as pneumonitis (a type of pneumonia) or a malignancy can develop, threatening the baby's life.

Also, the child's central nervous system can be affected, causing problems with development. He/she can have developmental lags, not attaining age-appropriate language and motor milestones, and he/she can regress, losing developmental milestones (Ultmann, et al, 1988).

The current life expectancy is four years for children born with HIV/AIDS; however, the earlier symptoms occur, the more severe the course of the disease and the higher the chance of an early death (Sokal & Ramler, 1991).

FOSTERING FAMILIES

Lecturette #4 (Cont'd)

CARING FOR AN AIDS BABY

An infant with HIV/AIDS has special medical and developmental needs that will require extensive medical treatment by a battery of medical personnel, eg. pediatricians, specialists, nurses, etc. It is important that foster parents become knowledgeable about the disease and medical terminology to insure proper care for the child. Being able to communicate with medical personnel is a required skill in caring for HIV/AIDS children.

Given the nature of HIV/AIDS, babies with the virus can get sick very quickly. Workers and foster parents need to be able to recognize illnesses in their earliest stages as any illness can be life threatening to these babies. The child's doctor must be called immediately if he/she has any signs of a fever, develops a new skin rash, suddenly become listless, fussy, or won't eat, or has increased shortness of breath or blueness (Sokal & Ramler, 1991). The foster care worker must work closely with medical staff, the foster parents, and where appropriate, the birth parent(s).

Infants with HIV/AIDS are very susceptible to common illnesses such as colds, ear infections, and diarrhea, and severe infections such as pneumonia and meningitis. It is important to protect these babies from exposure to such infections as much as possible. Any illness can have a severe consequence for a baby with AIDS. Thus, the HIV/AIDS infant must avoid close contact with another child or an adult who is sick--absolutely avoiding contact with someone with chickenpox or measles as these illnesses can be life threatening (Sokal & Ramler, 1991).

Individual Activity:

Read the story entitled "Aretha Brown's Mission: A Story of Love."

Group Activity:

Show video entitled "Caring for Infants and Toddlers with HIV Infection." Exercise #2 provides some questions to further discuss this video.

FOSTERING FAMILIES

VIDEO

Exercise #2

View video - "Caring for Infants with HIV"

After the video has been shown, divide into small groups of 5-6 people. In the groups discuss the video using the following questions as guidelines:

1. **Could you relate to the families in the video? What surprised you most about the parents you saw in the video? What surprised you the least?**

2. **How is being the parent of a child with HIV like being the parent of any child? How is it different?**

3. **If you were the foster parent of a child with HIV, how do you imagine it would affect your own day-to-day life and that of your family?**

4. **If you were the foster parent of a child with HIV, how would you and your family cope with the child's illness and probable death?**

5. **For caseworkers- As a service provider, how do you think you could be most helpful to foster families affected by HIV? In what areas would you want or need more training or experience?**

PRECAUTIONS IN CARING FOR AN AIDS BABY

One of the major concerns about caring for a baby with AIDS is the fear of contacting the disease from the infant. The AIDS virus is not easily transmitted and is transmitted only through sexual contact, blood, and contaminated needles. HIV has not been shown to be spread in households through casual contact, such as sharing space, sharing toys, hugging, and kissing. Therefore, caring for an AIDS baby poses little threat to the family and routine family activities can be carried out without fear.

Precautions need to be taken, however, when the caregiver is in contact with the child's blood and body fluids. Precautions suggested by the American Academy of Pediatrics Task Force on Pediatric AIDS (1988) include washing your hands immediately before and after changing the baby's diaper or being exposed to his/her body fluids and using disposable items such as towels and tissues when caring for the baby. In addition, clean soiled surfaces with a bleach solution, wash soiled clothes with bleach, do not share personal items such as pacifiers, and use disposable gloves when exposed to the baby's blood or blood-contaminated body fluids especially if you have an open skin lesion.

Although it is believed that AIDS babies who persistently bite others or have oozing skin lesions can transmit the virus, this has not been conclusively shown. A physician is the best source for care guidelines if the baby bites others or has lesions.

Individual or Group Activity:

Examine Chart E, entitled "Precautions in Caring for Infants with AIDS."

FOSTERING FAMILIES

PRECAUTIONS IN CARING FOR INFANTS WITH AIDS*

Chart E

1. **Wash your hands with running water and liquid anti-bacterial soap and dry with disposable towels or tissues immediately before and after changing the baby's diaper or being exposed to his/her body fluids. Gloves are not needed for changing his/her diaper unless you have an open sore or sores on your hands.**

2. **Dispose of towels or tissues after one use when caring for the baby. Dispose of contaminated items (diapers, paper towels, gloves, tissues) in a covered trash can lined with a disposable plastic bag.**

3. **Promptly clean soiled surfaces with a bleach solution prepared daily (one tablespoon bleach to one quart water if no blood present or one part bleach to 10 parts water for cleaning bloodied surfaces). Mops should be rinsed in the bleach solution. Toilets and tubs can be cleaned with the solution.**

4. **Avoid exposure of mucous membranes or any open skin lesion to blood or blood-contaminated body fluids by using disposable gloves.**

5. **Clothes soiled with blood should be washed with bleach, separate from other laundry.**

6. **Do not share personal items such as pacifiers or toothbrushes. All items that are washed between uses such as eating utensils and linen may be shared.**

7. **AIDS babies who persistently bite others or have oozing skin lesions may theoretically transmit the virus; however, this has not been conclusively shown. Ask your physician about guidelines if baby bites others or has lesions.**

*** American Academy of Pediatrics Task Force on Pediatric AIDS, (March, 1987). Pediatric guidelines for attendance in daycare and foster care settings of children infected with human immunodeficiency virus. Pediatrics, 79(3), 466-470.**

FOSTERING FAMILIES

Lecturette #4 (Cont'd)

Other preventive measures include keeping the house clean and free from molds, washing your hands before feeding the baby, and washing eating utensils well in hot, soapy water or in the dishwasher. The child's skin should be kept clean and dry, and diapers should be changed frequently.

FOSTER PARENT NEEDS

Because of their medical condition, AIDS babies require a great deal of time and energy. Much time will be needed for home health care, medical appointments, unexpected illnesses, hospitalizations, etc. Along with the time demands, foster parents must cope with the emotional and financial demands of caring for a sick baby whose condition is deteriorating and is probably going to die. They also face potential stigma and ostracism from family members and the larger community, along with possible legal action to protect their rights in caring for an AIDS baby.

Foster parents caring for AIDS babies need continual education about HIV/AIDS. This education should include information about caring for the child's special medical and developmental problems, coping with chronic illness, death and grief, knowing the legal rights of a child with AIDS, and finding available resources (Sokal & Ramler, 1991).

In fact, dealing with these multiple problems may be very difficult. Foster parents caring for an AIDS baby will need to limit the number of children in their care. They also need to be alert to signs of stress such as chronic feelings of sadness, anger, irritability, or fatigue. If these signs appear, it is

Individual or Group Activity:

Examine Chart F entitled, "Care Needs of HIV-Affected Children."

FOSTERING FAMILIES

CARE NEEDS OF HIV-AFFECTED CHILDREN*
Chart F

Feeding
* Adequate nutrition, balanced diet
* Pay attention to liquid intake to avoid dehydration

Problems Chewing/swallowing
* Special medicated tablets or mouth rinses
* Soft or liquid diet
* Cool foods vs. warm foods

Vomiting
* Clear liquids in small frequent amounts
* Bland, fat-free diet

Diarrhea
* Clear liquids in frequent small amounts
* BRAT (bananas, rice, applesauce, toast) diet

Illness Prevention
* Wash hands, bottles and eating utensils well
* No raw/unpasteurized milk or cheese
* Wash vegetables well; cook eggs, meat, seafood completely
* Do not let milk stand unrefrigerated; do not put baby to bed with a bottle of milk

Skin Infections
* Keep child's skin clean and dry; use mild lubricants & soaps
* Change diapers frequently; keep child's bottom dry
* Keep nose and face clean when child has a cold
* Take temperature under baby's arm and not in rectum

Warning Signs to Call the Doctor
* New skin rash
* Sudden listlessness, fussiness, poor appetite
* Increased shortness of breath or blueness
* Fever over 101 F./38.5 C.
* Exposure to chicken pox or measles

*Reprinted by Permission From: Sokal, Karen & Ramler, Malia (1991). Care needs of HIV-affected children. Children, Families, & HIV A training curriculum for social service and health providers. Berkley: University of California.

time for them to take a break. Hobbies and activities that help relieve stress should be maintained. Respite care is a must so that they can spend time alone or with family and friends. A good family and peer support system is also necessary, and formal support services including parent support groups through hospitals, social workers, etc., are also recommended.

Along with stress, foster parents need to be prepared for feelings of anger and resentment toward the birth parent(s). It is important that they be prepared to deal with those feelings along with feelings of ambivalence about family reunification if the birth mother is actively involved in a treatment plan. Chances are, however, that the parent(s) are either too ill to resume care of this baby or are not available because of continued drug use.

Foster parents need to be realistic. Caring for an ill child who will probably die, is difficult for all family members. Death is a part of life, but the death of a child is often hard to understand. It is important for family members to talk openly about their feelings and fears around the death of the child and to be prepared for a time of grief following the child's death. Spiritual and popular books are available to help in the grieving process as are support groups.

CONCLUSION

The symptoms of AIDS in babies have been identified along with some basics about caring for these infants, the needs of the foster parents, and the precautions required. Regardless of the special needs, AIDS babies still need the same love and nurturing as other babies. In fact, they survive longer in foster placement than if left in the hospital with no family present.

FOSTERING FAMILIES

ARETHA BROWN'S MISSION: A STORY OF LOVE

Several hours before midnight on New Year's Eve, 1990, Isaiah Cooper, who had been admitted to the Weiler Hospital Division of the Albert Einstein College of Medicine a little over a month earlier, went into cardio-pulmonary arrest and was officially pronounced dead. He was five and a half years old and had been infected since birth with the human immunodeficiency virus causing AIDS.

In the weeks preceding his death, Isaiah's foster mother, Aretha Brown, who had begun caring for the boy when he was only nine months old, had spent long hours on the ward watching over him and satisfying her exacting sense that all that could be done for him was being done.

"She was often there from early in the morning until late at night, sometimes until 3 or 4 a.m.," explains the nurse case manager assigned to Isaiah at the time by the Leake and Watts Specialized Foster Boarding Home Program. "We all told her that it was dangerous to be traveling home that late at night, but she didn't seem to mind. She had a kind of unspoken contract with Isaiah - he trusted that she would always be there for him, and she was. It was like a mission for her."

Now, in the moments after his death, she was allowed by staff to bathe the child before his small body was removed from the ward. Mrs. Brown appreciated the chance to care for Isaiah one last time, and she expressed her appreciation both to the hospital staff and, in a telephone conversation, to her nurse case manager. "After we talked for a short time," the manager wrote in her progress notes that evening, "[Mrs. Brown] ended the conversation, stating she wanted to relax."

The events of the past month or so had certainly taken their toll on Mrs. Brown and her family, but, then, nearly the whole of 1990 had been difficult. In March, the eldest of her two foster children, Raymond, age nine, had died from the effects of HIV infection. The loss of Raymond was especially difficult for Mrs. Brown not simply because he was her first foster child to die, but because she had worked so hard to try to offset the effects of his considerable developmental delays. The hard work had produced results. "He was our miracle child!" Mrs. Brown would later say. "He made so much progress." After Raymond's death, Mrs. Brown experienced a void that even today she struggles to describe. "My life was so full until then," she simply says.

There was another foster child to care for, however, along with three grown daughters, all of whom were living at home. Thus, despite her feelings of loss, Mrs. Brown resolved "to be there" for Isaiah. To do this, she knew that she needed to regain control of her emotions - to, as she would later put is, "think on a professional level, like a social worker."

Isaiah seemed mollified by Mrs. Brown's attempts to explain Raymond's death. "He was not that aware," she now says. "He seemed to accept what we told him, which was that Raymond had gone to heaven."

Medically, however, Isaiah presented more difficult problems: his condition, at this point, was worsening.

During his first couple of years with Mrs. Brown, Isaiah was a jolly, active child whose occasional ear infections and episodes of fever and diarrhea were typically treated during a clinic or emergency room visit or, in more serious instances, during a brief hospital stay. His overall condition was monitored closely during monthly visits to the pediatric immunology clinic, and, as a standard prophylactic measure, he also received biweekly infusions of intravenous gammaglobulin, which served as a kind of booster to his own less-than-healthy immune system. In general, he was doing fairly well and was even regularly attending day care, which he appeared to enjoy. A summary of a home visit conducted around the anniversary of his first year in placement notes: "Child appears well; he is very friendly and very attached to the foster mother; child is speaking more and walks very well; he is eating and sleeping well and has no current medical problems."

By the end of his second year in placement, Isaiah was still doing nicely. Along with the other members of the Brown household, he enjoyed the picnics and outings that Mrs. Brown arranged during the summer months at Van Cortland Park. The highlight of the year was a three-day trip to Disney World, sponsored by the Starlight Foundation.

Together with the social worker from Leake and Watts, the family departed by airplane to Orlando, Florida. While on the airplane, however, Isaiah became ill and, once on the ground, had to be taken to Humana Hospital, where doctors prescribed medications for bronchitis. Although his condition improved sufficiently so that he could enjoy the remainder of the trip, he became ill again once back home, this time with a bilateral ear infection and an accompanying fever of 103 F. As with the bronchitis, the ear infection was successfully treated and, in a few days, Isaiah returned to day care.

The problems during the Disney World trip and return home were not atypical for Isaiah, yet, in retrospect, they marked a subtle shift in the balance of his health. While still an active, jolly child nearing his third birthday, Isaiah was beginning to display an alternating pattern of sickness and well-being. At this point, fortunately, he was more often well than sick, but the pattern had begun to emerge and in the following months would become more

pronounced. A note written in August 1988 by the social worker recently assigned to Isaiah and the Brown family calls attention to the child's mercurial health: "Isaiah is looking better than he has the past couple of times I've seen him, but his medical problems are so serious that he can look good one day and bad the next. The foster mother says he's spoiled because everyone in the family loves him so much that he always gets his way, [but] he is a very attractive youngster. And the foster mother takes excellent care of all the emergency medical situations he presents."

At the end of November, Isaiah experienced a particularly stubborn episode of what was by now chronic otitis media or inflammation of the middle ear. He was also febrile, and when his temperature rose to 103 with Tylenol, he was admitted to Albert Einstein Hospital.

An affecting note written by the nurse case manager after visiting Isaiah in his hospital room describes the child's poor condition: "[Isaiah] looked very ill and seemed to be in pain. It was very difficult for him to move into different positions. His legs hurt and his feet were swollen. He was unable to stand. His conjunctiva were red, although his eyes didn't seem infected. [Isaiah] was sad. 'Help me, hold me,' he asked. He wanted to sit on my lap, and for the one and a half hour [that I held him, he] was too ill to be interested in any of his toys. I left after two hours, at which time I returned him to his crib and settled him as comfortably as possible."

A few days after this visit, Isaiah began to respond to the intravenous antibiotics that had been prescribed for him, and, by day six in the hospital, he was clearly doing much better. While in the hospital, however, doctors also became concerned that Isaiah's liver might be infected. The child had a history of liver problems that was thought to be the result of his prenatal exposure to syphillis. He had been treated for syphilis as a newborn, but had gone on to develop chronic hepatitis B, with what the doctors referred to as "fluctuation liver cell enzymes." In fact, three months before this current hospitalization, a surgical procedure to diagnose the cause of his persistent middle ear problems had to be postponed because of high liver cell enzyme levels. This time around, however, the hepatitis B screen indicated only past exposure to the virus but no active infection. Among other things, this meant that, once out of the hospital, Isaiah would be medically cleared to return to the day care center, at least for the time being.

Despite significant periods of wellness during the first several months of 1989, Isaiah continued to require treatment and, on one occasion, hospitalization for a variety of AIDS-related medical problems. In late May, Mrs. Brown busily made preparations for taking Isaiah and his foster brother Raymond to a camp in California for HIV-positive children. The trip to Camp Sunburst was arranged by the social worker at Albert Einstein Hospital. Upon her return, Mrs. Brown pronounced the trip a real success, with Isaiah doing especially well at the various camp activities.

A STORY OF LOVE (CONT'D)

Medically, the remainder of the year followed what was by now a fairly well-established pattern: periods of wellness alternating with occasional emergency medical interventions, and, through it all, of course, a constant round of clinic and other provider visits. By late in the year, Isaiah was being evaluated for a special pre-school program, and Mrs. Brown, in coordination with the Leake and Watts social worker, was doing her part to make certain that he was accepted.

Once again her efforts proved successful, although Isaiah's actual starting date in the program would be delayed by several months. Meanwhile, Raymond's condition was deteriorating rapidly, while Isaiah's medical problems, though not yet acute, were clearly becoming more pronounced. By the time of Raymond's death in March, 1990, more than one observer had concluded that Isaiah's own condition was deteriorating.

One of the problems observed at this point was his frequent falling. In late March, Mrs. Brown, accompanied by the nurse case manager, took Isaiah for a neurological evaluation at the Rose F. Kennedy Center. The neurologist performing the evaluation concluded that Isaiah's frequent falls and unsteady gait were the result of developmental delays and progressive neurological infection. Physical and occupational therapy sessions were arranged for him, and a special stroller and other equipment ordered for home.

In late May, Isaiah finally began school. The pre-school program was designed for special-needs children, and Isaiah seemed to adjust well to his new regimen. The time Isaiah spent at school also provided a welcome, if partial, respite for Mrs. Brown. But Isaiah frequently missed classes because of his recurrent medical problems - ear infections, congestion, rashes, and bouts of fever and diarrhea.

He was hospitalized in June, July, and again in August, this last time when a chest x-ray revealed the presence of a pneumonia of undetermined kind. Isaiah's doctor suspected that it might be a viral or bacterial pneumonia, rather than the more difficult-to-treat pneymocystis carinii pneumonia (PCP), which, as clinicians have discovered, is perhaps the most frequently encountered opportunistic infection in pediatric AIDS cases and which, in fact, had been the cause of Raymond's death. As it turned out, Isaiah had a less serious form of pneumonia, which responded fairly well to treatment. He was discharged from the hospital after seven days and placed on a variety of medications. His nurse case manager also made arrangements for a nebulizing machine to be delivered to the Brown home. All agreed the treatment was a good idea, although it was known that the medicated spray the machine would suffuse into the child's lungs would serve only to comfort him, and not, as was more typically thought, to prevent a reoccurrence of his infection.

FOSTERING FAMILIES

A STORY OF LOVE (CONT'D)

Isaiah had managed to pull through this latest illness, but he was doing poorly. In a note written on the day of his hospital discharge by his original nurse case manager, who had not seen him in three years, Isaiah's present condition is described in disturbing detail: "When I was his nurse he appeared well in every aspect," she wrote. "[Isaiah] now has a severe skin condition that covers most of his face and body; his right eye turns in and his left eye turns up; his hair is brittle and sparse and his gait is unsteady."

By the end of September, he was back in the hospital again for his chronic respiratory problems, and, as before, his doctor was eager to rule out a diagnosis of PCP. After more routine tests proved inconclusive, a request for permission to perform a bronchoscopy - the insertion of a lighted tubular instrument into the trachea for removal of possibly infected lung tissue - was faxed and approved by the Child Welfare Administration (CWA), which was required to approve all such invasive diagnostic procedures. Mrs. Brown was afraid that, in his present weakened condition, Isaiah would not be able to tolerate the procedure, and she argued against it. As a Jehovah's Witness, she was also disturbed when informed that the doctor planned to give Isaiah a transfusion to build up his red blood cell count. Legally, of course, Mrs. Brown could not prevent either procedure, since Isaiah was under the guardianship of CWA; but no one, least of all the nurse case manager, wanted to lose the trust of this extraordinarily committed foster mother. After the nurse case manager explained the rationale for each procedure and permitted Mrs. Brown to "verbalize her feelings," she relented, and both the transfusion and bronchoscopy went forward.

The bronchoscopy, as it turned out, revealed the presence of a virus (cytomegalovirus or CMV) somewhere in Isaiah's system, but it was not conclusive. In the end, an open lung biopsy had to be performed, again to the initial dismay of Mrs. Brown. This biopsy also proved inconclusive, revealing only "some non-specific infectious cells."

Isaiah entered the hospital for the last time just after Thanksgiving Day, 1990. He was having extreme difficulty breathing; tests showed he simply was not getting enough oxygen. After a time, a chest tube was inserted to re-expand his partially collapsed right lung, and instruments were set up to monitor his heart rate, blood oxygen level, etc.

Mrs. Brown feared this was the beginning of the end, and, though in conversations with the nurse case manager she sometimes cried and talked about her sadness, she closely followed and monitored nearly every detail of Isaiah's care and treatment. She was particularly concerned when she learned from the nurse case manager that a committee comprising hospital and agency staff had drafted a "Do Not Resuscitate" (DNR) proposal.

FOSTERING FAMILIES

A STORY OF LOVE (CONT'D)

The committee's decision, of course, was far from definitive, since first the commissioner of CWA would have to be notified, and then the hospital's Ethics Committee would have to agree to the proposal before passing it on to CWA for final approval. Still, Mrs. Brown remained upset about the precise meaning of the proposed DNR order until the nurse case manager explained to her that Isaiah would receive all medical care, but should he go into cardiac arrest, he would not be placed on a ventilator.

Isaiah's condition continued to worsen throughout early December and, by mid-month, arrangements had been made for him to spend his remaining days in a children's hospice in Queens. At first, Mrs. Brown had requested that Isaiah be allowed to die at home, but she soon came to acknowledge that the hospice was now the far better place for the child to whom, for the past four and a half years, she had devoted so much of her love and energy.

On the morning of the day that Isaiah was to be transferred from the hospital, three members of his Leake and Watts foster care team were already at the hospice in Queens busily preparing for his arrival. His accommodations were set and the staff had even prepared a mailbox with his name on it. At 10:30 a.m., the hospital called the hospice to inform them that "[Isaiah] was too unstable to be transferred at this time." Ten days later he was dead.

At his funeral, two of Mrs. Brown's daughters read eulogies to their much-beloved foster brother, eulogies that Mrs. Brown had helped them compose and that reflected the indomitable spirit she had sought to cultivate in all her children, whatever their last names. The eldest daughter had been especially touched by the spirit of her "youngest brother and best friend," and in her eulogy she paid moving tribute to it:

[Isaiah] was strong through his sickness; when the doctors said "No," he said "Yes." When they said "Go," he said "Stay." And when they said "How," he said "Watch." So you see, he fooled a lot of people for a long time. But I guess that's what five year olds do.

Used here by permission of Pediatric AIDS Foster Care NETWORK BULLETIN by Leake & Watts, Volume 3 Number 2, Summer 1991.

FOSTERING FAMILIES

CARING FOR MEDICALLY FRAGILE INFANTS IN FOSTER CARE

Lecturette #5

This last section serves as a summary for the many aspect of medically fragile infants that has been addressed. This section summarizes the important care-taking aspects of medically fragile drug and alcohol exposed infant. As you have read through this material, hopefully, you saw frequent points of similarity. Some of these similarities emerged from prenatal exposure to drugs; other similarities are apparent in the delayed development of these babies. On the next several pages, we provide several charts that address techniques to comfort, interact, and care for drug exposed babies.

CARING FOR MEDICALLY FRAGILE INFANTS IN FOSTER CARE

Foster parents and workers need to be aware that drug and/or alcohol exposed infants are usually irritable, difficult to handle, have medical problems that need special attention, and require extra one-on-one interaction. This may take an extraordinary amount of time, energy, and patience. In addition, a quiet, structured environment is needed as these infants can easily reach a frantic state if exposed to multiple stimuli at one time.

Because of these special needs, workers need to be prepared to advocate for foster home parents when considering placement of a drug exposed baby. Workers need to stay in close contact with medical personnel as well as with the foster family.

FOSTERING FAMILIES

Lecturette #5 (Cont'd)

Bonding with these infants may also be difficult but is possible. The best time to work at bonding is when the baby is awake and calm. Swaddling (wrapping tightly in a blanket) and giving him/her a pacifier helps reduce stimulation so that he/she can tolerate eye contact and voices. Holding the baby vertically, facing him/her, and gently rocking in an up-and-down motion will often cause the baby to open his/her eyes and look at you. Use one stimulation at a time, for instance, either rock or talk to the baby rather than doing both at the same time (Griffith, 1988).

Because of the infant's fragile physical and emotional condition, working closely with medical personnel is essential in understanding the infant's medical history, physical defects, and potential medical problems. Foster parents and workers must become familiar with medical terminology, protocols, and procedures, recognizing that the field is continually changing. Find out how thoroughly and by whom the baby has been evaluated. And ask questions!

Some questions that foster parents and workers might ask medical personnel are:

- **What drug or drugs did the mother use? What apparent effects does the baby have from that drug/ drugs or alcohol?**
- **What physical defects, if any, does the child have? Do these problems require special care?**

<u>Individual or Group Activity</u>:

Examine Chart G entitled, "Comforting and Interacting With Drug Exposed Infants."

Examine Chart H entitled, "Techniques for Caring for Drug/Alcohol Exposed Infants."

FOSTERING FAMILIES

COMFORTING AND INTERACTING WITH DRUG EXPOSED INFANTS
Chart G

1. Avoid allowing infant to reach a frantic cry state

   a. Be aware of and respond to early distress cues (e.g., yawns, sneezes, hiccoughs, motor agitation, color changes, frowns and eye aversions).

   b. If the above is seen, stop what you are doing and give the baby some time to recover.

   c. If the baby is unable to regain control, go to Step 2.

2. When the infant reaches a frantic cry state, try to calm immediately. The sooner the infant is calmed, the easier it will be to calm him/her.

   a. Use swaddling first, followed by a pacifier. The frantic crying infant is frequently not well-enough organized to even suck on the pacifier.

   b. If the above does not work, hold infant closely and rock, especially in the vertical position.

3. Stimulate infant in ways he/she can tolerate (for example, take advantage of times when infant is awake and calm to work on orientation to face or voice).

   a. Use one stimulus dimension at a time initially - voice or face.

   b. Watch for infant's cues mentioned in #1a and allow time out.

   c. Infant may require swaddling and/or pacifier to reach or maintain an alert responsive state.

4. Gradually increase the amount of interactive visual, auditory, and tactile play with infant. Let the infant be your guide. His/her cues will tell you what he/she can tolerate, enjoys or dislikes.

5. When infant is calm, unwrap him/her to allow him/her to become used to controlling his/her own body movement. Reswaddle if and when he/she begins to lose control of movements (For example, frantic diffuse activity).

Reprinted by permission. Adoptive Parent Packet, Dan R. Griffith, Ph.D. Developmental Psychologist, National Association for Perinatal Addiction Research and Education

FOSTERING FAMILIES

TECHNIQUES FOR CARING FOR DRUG/ALCOHOL EXPOSED INFANT
Chart H

There is a high chance that an infant will experience symptoms from the various substances he/she was exposed to during pregnancy. The symptoms can last up until the sixth month of life or longer.

Infant Behavior	Caregiver Intervention
Prolonged and/or high-pitched cry	Soothe infant by holding snugly and close to your body. Swaddle with a blanket if he/she is too active for you to hold snugly.
Inability to sleep	Reduce environmental stimuli, such as loud noises, bright lights and excessive manipulation. Don't handle baby too much. Soft voice, humming, or rocking may be soothing. Decrease the time between feedings or start a demand feeding schedule.
Frantic sucking of fists	Use infant shirts with sewn-in sleeves for mitts to prevent damage to the skin. If skin is damaged (e.g. scratched by infant's own nails), keep affected skin area clean with a mild soap and water. Use a pacifier.
Sneezing, nasal stuffiness and trouble breathing	Clean nose frequently if plugged with mucus or dried formula. Don't restrict chest movements with tightly wrapped blankets (i.e., swaddling). If baby's skin color appears very pale, grey or blue, call the doctor immediately. If baby appears to be breathing too fast, count the number of times he/she breathes for one full minute, and if he/she is breathing 60 times or more, tell the doctor. Feed smaller amounts of formula more often. Allow more time for feeding, with rest periods between sucking. Keep infant in a sitting position.

Chart H (Cont'd)

Infant Behavior	Caregiver Intervention
Poor feeding Spitting up Vomiting	Feed small amounts of formula frequently. Take extra time to burp baby gently and well. Feed baby slowly if he/she begins to "gulp" or vigorously suck on nipple. If baby is sucking poorly, support chin and both cheeks to increase sucking ability. If baby has been vomiting or spitting up, keep him/her on his/her side or stomach to prevent breathing in vomited formula. Clean skin area with mild soap and water immediately after infant has vomited or spit up because stomach contents contain acid which can irritate and damage skin.
Stiffness or rigidity Hyperactivity Trembling	Bathe baby frequently in warm water with mild soap and and dry well. Ask doctor if medicines, ointment or cream are needed or recommended. Change position frequently (every half hour). Position baby on soft flannel blankets or a sheepskin. Expose raw (or "rubbed") area of the baby's skin to the air or use a heat lamp every 2-3 hours (ask nurse to show you how to do this). Decrease environmental stimuli (noise and too much handling).
Fever (temperature of 100 degrees or more)	Do not swaddle. Remove extra covers. Reduce clothing to shirt and diaper only. Decrease room temperature. Sponge baby in lukewarm tap water.

Reprinted by permission from: National Association for Perinatal Addiction Research and Education, Chicago, Illinois

* What medical problems could the baby face?
* What are some symptoms of such problems?
* How do I care for the child's medical problems? Will he/she outgrow the problems?
* Has the baby been evaluated for neurological and motor development at birth and how often since?
* Has the baby been screened for AIDS?

Another important aspect for workers and foster parents in caring for these infants is to be aware of their feelings toward the biological mother. Some questions workers and foster parents need to ask themselves are:

* Do I blame her for the child's condition?
* What would I do if she comes to visit the child and is drunk or high?
* How would I feel if she has gone through drug/alcohol rehabilitation and wants custody of the child?

FOSTER PARENT NEEDS

Because of the extraordinary amount of time and energy needed to care for these infants, foster parents need to take extra steps in caring for their own needs. They need to be aware of how they manifest stress and be alert to signs that they need to take a break. If one has chronic feelings of fatigue, sadness, hopelessness, and confusion, is irritable frequently and has angry outbursts, and burst into to tears at unexpected moments, he/she is showing signs of stress.

Individual or Group Activity:

Examine Exercise #3 entitled "Practice Situation: AIDS Baby."

Respite childcare should be lined up so that the foster parent can spend time away alone or with family in pleasurable activities or hobbies. It is important to maintain hobbies and activities that help relieve stress.

Also, informal networks or support groups with other foster parents caring for drug and/or alcohol exposed infants can break feelings of isolation, provide an understanding ear, and provide practical suggestions on caring for these infants.

In addition, it may be necessary to limit the number of foster children in a foster home when caring for a drug exposed infant in order to adequately provide the care the infant may require.

CONCLUSION

Medically fragile infants who have been exposed prenatally to drugs or alcohol are the fastest growing segment of children entering the foster care system. Along with physical and developmental problems, these children may be irritable, difficult to care for, and have problems with bonding. Foster parents need to be aware of the demands of caring for such infants. With knowledgeable, patient, and loving caregivers, these infants can and do thrive.

Individual Activity:

Consider the questions posed in Exercise #4, which serves as the Homework Assignment for trainees seeking partial University credit.

FOSTERING FAMILIES

PRACTICE SITUATION
AIDS BABY

Exercise #3

Two months ago, one-month old Patrick was found in a trash can. His 18 year old mother had wrapped him in a plastic bag and abandoned him to die when she found out she was HIV positive. A teenage boy, Jonathan, found Patrick and called the police.

After Patrick was treated at General Hospital, social services placed him in a foster home. Jonathan has been helping the foster family two days a week since Patrick came to the foster home. He is very committed to helping since he feels he was responsible for Patrick still being alive.

Today, the foster mother, Charlotte Milton, learned that Patrick has pneumonia and may not live more than a week or so. She learned that AIDS does not kill – rather, opportunistic diseases (infections caused by germs that can not be fought off by weak immune systems) such as pneumonia often are responsible for the death.

Charlotte has asked that the social services worker talk with Jonathan because she feels she is just too "emotional."

In small groups, discuss the following questions related to this situation:

1. **Is Charlotte right in asking social services to talk to Jonathan?**
2. **How would we feel in this situation? What would we do?**
3. **What might be needed for the foster family at this time?**
4. **Discuss what the worker might actually say to Jonathan?**

FOSTERING FAMILIES

HOMEWORK ASSIGNMENT
Exercise #4

This training module has identified great demands for workers and foster parents who work with drug-exposed infants. As well, serious problems exist for drug-exposed babies in out-of-home care situations.

The following questions could help training participants think through other issues and concerns that are not as yet addressed.

1. **How much should the caseworkers be involved in monitoring the daily care issues when the foster family is caring for a fragile drug-exposed baby?**

2. **What type of treatment planning issues might be unique to this population of children?**

3. **Since most of these babies are receiving medical attention through medicaid, could there exist problems gaining access to quality medical care?**

4. **There is great social stigma for AIDS children and the families who care for them. What efforts should be taken to help workers and foster parents cope with their won issues with AIDS, and further, how could foster families be supported when community problems arise around an AIDS child in their home?**

Mail your completed work to:

Dr. Mona S. Schatz
Fostering Families
Colorado State University
Social Work Department
202 Eddy Building
Ft. Collins, CO 80523

FOSTERING FAMILIES

KEY POINTS IN THIS MODULE

1. **Because of possible withdrawal symptoms, physical problems, mental retardation, developmental delays, learning disabilities, behavior problems, and/or AIDS, alcohol and/or drug exposed children require extraordinary time and care. In most cases, ongoing one-on-one care may be required throughout the child's development. These factors need to be considered in the placement and assessment process as well as in permanency planning.**

2. **Alcohol and/or drug exposed infants can be irritable and cry a lot. There may be occasions when caregivers cannot console them no matter what they do. These children may also resist eye contact or being touched. It will take extra one-on-one work to help these children bond.**

3. **Working closely with medical personnel and other specialists is critical in assisting the alcohol and/or drug exposed child and the child with AIDS. Caregivers need to be informed about past medical history of the infant, present medical difficulties, and potential medical problems.**

4. **Caregivers of alcohol and/or drug exposed children and babies with AIDS need to set aside time for themselves. It is also important to maintain hobbies or activities that help relieve stress. Support organization made of other caretakers of these children can provide information, perspective, and someone with an understanding ear.**

5. **Workers and caregivers of AIDS babies need to be aware that the child's medical condition will worsen and the child will probably die. It is important to be aware of the grief process following the death of a child.**

FOSTERING FAMILIES

SUGGESTED RESOURCES: FETAL ALCOHOL SYNDROME

Dorris, Michael (1989). The Broken Cord: A Family's Ongoing Struggle with Fetal Alcohol Syndrome. New York: Harper & Row. Cost: Hardback, $18.95, Harper Perennial Paperback, $9.95.

This book details the author's struggle with parenting his adopted Sioux Indian son who has FAS. In recounting his struggle, he intertwines statistics and consequences of FAS.

Fetal Alcohol and Drug Unit, Barbara VonFeldt, Information Director, 2707 NE Blakeley, University of Washington, Seattle, WA 98195.

Write to this facility for an information packet on FAS. There is no charge for the packet but contributions are requested to covered costs. Make check payable to FAS Research Foundation.

Fetal Alcohol Syndrome Information Service. (1991). Iceberg. P. O. Box 4292, Seattle, WA 98104.

This is a quarterly educational newsletter that gives useful information about FAS/FAE and lists upcoming conferences and events related to FAS/FAE. Subscription rate: $5.00, family yearly rate or $15.00, professional yearly rate. Subscribe by sending a check to ICEBERG at the above address.

Growing with FAS. Groves, Pamela (Ed.), 7802 S.E. Taylor, Portland, OR 97215.

This is a newsletter that offers support to caretakers of FAS/FAE children through personal accounts of caretakers of these children. It is published about every two months and can be obtained by sending $2.00 for each issue to the above address.

Streissguth, Ann P., LaDue, Robin A., & Randels, Sandra P. (1988). A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians. Indian Health Service, Maternal and Child Health Branch, 5600 Fisher's Lane, Rockville, MD 20857. 301-443-1087. 55 pp. No charge. This manual identifies and describes characteristics of FAS and FAE and includes developmental stages and relevant characteristics of each stage. It also describes a follow-up study of 61 patients with FAS and FAE and presents recommendations for helping adolescents and adults with FAS/FAE and their families.

SUGGESTED RESOURCES: DRUG-EXPOSED INFANTS

Chasnoff, Ira J. (ed.) (1988). Drugs, Alcohol, Pregnancy, and Parenting. Kluwer Academic Publishers, P. O. Box 358, Accord Station, Hingham, MA 02018-9990. Cost: $44.50

This book is geared toward health care professionals who work with drug-using mothers and their infants. It does give useful information on physical effects of drugs and alcohol on the developing fetus and caring for a drug exposed infant.

Levy, Stephen J. & Ruther, Eileen (1992). Children of Drug Abusers. New York: Lexington Books.

This book is geared toward professionals who work with children of drug abusers. It gives information on drug-exposed infants and on children living in substance abusing environments or in foster care. Intervention and treatment strategies are addressed.

National Association for Perinatal Addiction Research and Education. (1991). NAPARE Adoptive Parent Packet. NAPARE, 11 E. Hubbard St., Suite 200, Chicago, IL 60611.

This packet contains useful information about the effects and the care of infants exposed to drugs or alcohol in utero. NAPARE also has a Cocaine Baby Help Line, 800-638-BABY or 312-908-0867.

National Resource Center for Special Needs Adoption. (1991). Training Tape for Caretakers of Drug Babies. P.O. Box 337, Chelsea, MI 48118. Cost: $89.00 plus shipping & handling.

This video is aimed at foster parents, other caretakers, and social workers. It discusses some of the problems and special needs of babies exposed to drugs in utero. Suggestions are also given on how to soothe, relax and comfort these babies.

SUGGESTED RESOURCES: HIV/AIDS INFANTS

Child Welfare League of America. (1991). Meeting the Challenge of HIV Infection in Family Foster Care. Washington, DC. Can ordered from the Child Welfare League, c/o CSSC, P.O. Box 7816, 300 Raritan Center Parkway, Edison, NJ 08818-7816. Cost: $10.95.

This book is aimed at child welfare workers. It examines the complicated problem of foster care for children with HIV/AIDS and policy issues involved. Child Welfare League of America. (1991). Caring for Infants and Toddlers with HIV Infection. Video available from the Child Welfare League, c/o CSSC, P.O. Box 7816, 300 Raritan Center Parkway, Edison, NJ 08818-7816. Cost: $59.95

This video explores the day-to-day life of three families caring for infants and toddlers with HIV. It gives valuable information about caring for these children.

Gurdin, Phyllis & Anderson, Gar. R. (1991). Specialized foster care for children with HIV. In N. J. Hochstadt & D. M. Yost (eds.), The Medically Complex Child, pp. 219-228. New York: Hardwood Academic Publishers, c/o STBS Order Dept., P.O. Box 786 Cooper Station, New York, NY 10276. $25.00

This chapter explains the challenges for foster families in caring for children with HIV. The book in general gives good information on the various needs of medically complex children and the system of services necessary to meet their needs.

National Association of Children with AIDS, P.O. Box 15485, Durham, NC 27704. (919)-477-5288. National organization that can provide information on AIDS. Write or call to obtain information.

The Pediatric AIDS Foster Care Training and Technical Assistance Project. (1991). Pediatric AIDS Foster Care Network Bulletin. Leake & Watts, 487 South Broadway, Suite 201, Yonkers, NY 10705, 914-376-4415.

This is a quarterly educational newsletter geared toward foster care of children with AIDS. It can be subscribed to by writing Leake & Watt at the above address.

FOSTERING FAMILIES

Colorado State University
Application for Partial Credit

Module No.: SW_ _ _ _-_ _ _

Name: _____ **Social Security #:**_____

Address: _____ **Phone:** _____

_____
(city) (state) (zip)

Grading: __Pass/Fail__ **(unless otherwise requested)**

The Social Work Department at Colorado State University will grant university credit for each six different modules of training completed. Applications for credit must be made at the Time of Each Module Training ONLY. All work carried out in the modules must meet general academic standards of Colorado State. Written materials must be submitted and receive satisfactory grading for credit to be awarded. These applications will be held until the applicant completes his/her sixth module training. At this point, s/he will be able to formally register through the Division of Continuing Education for 1 credit hour. One credit hour of these modules costs $90.

FOSTERING FAMILIES

FETAL ALCOHOL SYNDROME
CRACK AND AIDS BABIES

EVALUATION BY PARTICIPANTS

The following items are designed to assess your satisfaction with the training as well as the effectiveness of the training design and materials. Please use the following scale and circle your response.

1 - not well addressed in the training
2 - not as adequately addressed as necessary
3 - adequate; given sufficient attention
4 - well addressed in the training
5 - very well addressed in the training

		Not Well Addressed				Very Well Addressed
1.	Through discussion and presentation of materials, participants will be able to identify the difficult foster care concerns for medically fragile infants who have been prenatally exposed to and affected by alcohol and/or drugs or may be suffering from AIDS. This will enhance the our-of-home placement, assessment, and ongoing case-monitoring processes	1	2	3	4	5
2.	To improve the case planning and placement process, participants will learn to identify some of the signs, symptoms, and behaviors of children who have Fetal Alcohol Syndrome or Fetal Alcohol Effects, who have been exposed prenatally to drugs, or who have AIDS	1	2	3	4	5
3.	To enhance the caregiving in the placement process, trainees will examine important components of working with these children such as assisting them with attaching behaviors, helping to calm them down when overstimulated, and providing a relatively tranquil environment	1	2	3	4	5
4.	To improve case supervision and management, workers and foster parents will learn personal coping skills to work with these special need alcohol/drug exposed babies	1	2	3	4	5

B. The following items relate to program aspects of the training module. Please rate these items on the following scale. Any additional comments are welcome in the space provided after the question.

1 = Very Poor
2 = Poor
3 = Adequate
4 = Good
5 = Very Good

	Very Poor	Poor	Adequate	Good	Very Good
1. The length of the training (Was the material covered in the time allotted?)	1	2	3	4	5
2. Usefulness of training manual	1	2	3	4	5
3. Participant responsiveness	1	2	3	4	5
4. Your ability to participate expressing your ideas, feelings, and concerns	1	2	3	4	5
5. Your interest in the training session	1	2	3	4	5
6. Your comprehension of the material presented	1	2	3	4	5

COMMENTS: Please be specific:_____

C. We are interested in your feedback about our trainer, co-trainer(s). With this feedback we can continue to improve our sessions.

1 = Totally inadequate and ineffective
2 = Generally inadequate and ineffective
3 = About half and half
4 = Usually adequate and effective
5 = Highly adequate and effective

	Totally Ineffective/ Inadequate				Highly Effective/ Adequate
1. Knowledge/mastery of the subject matter	1	2	3	4	5
2. Preparation	1	2	3	4	5
3. Ability to communicate	1	2	3	4	5
4. Style of presentation	1	2	3	4	5
5. Enthusiasm/interest in subject matter	1	2	3	4	5
6. Overall performance	1	2	3	4	5
7. Ability to facilitate	1	2	3	4	5

8. In general, what would you identify as the strengths of trainer(s)?

9. In general, what would you identify as the deficiencies of trainer(s)?

D. The training setting is obviously an important aspect of a sessions success. We are interested in your feedback regarding the location, room, etc., and again welcome any comments or suggestions.

	Very Poor	Poor	Adequate	Good	Very Good
1. Setting appropriate for concentration, i.e., distraction, noise, temperature.	1	2	3	4	5
2. Setting conducive for participation	1	2	3	4	5

COMMENTS: Please be specific:

E. Overall Comment: What could have been done differently to make the training sessions more beneficial or helpful to you? (Please use back of page if necessary).

I.D. #_ _ _ _

FOSTER CARE DEMOGRAPHICS

E. DIRECTIONS: Please fill in all blanks with information where needed or circle the correct number where several choices are provided on the next two pages.

1. Last 4 #'s of Social Security # _ _ _ _

2. Circle correct role: 1. worker 2. foster parent 3. Other_____
(please specify)

3. Date _ _ - _ _ - _ _

4. County _____

5. Circle gender: 1. Male 2. Female

6. Circle racial background:
1. Hispanic
2. Black, not of Hispanic origin
3. Asian-American
4. American Indian
5. White, not of Hispanic origin
6. Other:_____

7. Age_____

8. Are you (please circle one): 1. Married 2. Separated 3. Single

9. Number of birth & adopted female children_____

10. Number of birth & adopted male children_____

11. Circle age group of birth & adopted children:

1. all under 5
2. all under 10
3. all under 15
4. all under 18
5. all over 18
6. some under 18 & others over 18
7. none

12. Highest level of formal education: (please circle one)

1. some high school
2. high school graduate
3. some college
4. college graduate
5. Master's degree or higher

13. Within the past year, have you participated in any other foster care training other than Colorado State's Fostering Families?
1. yes 2. no

Thank you for your help! Your feedback is important for our continuing improvement of the Fostering Families project.

PLEASE CONTINUE TO THE NEXT PAGE

F. DIRECTIONS: Finally! Complete only the section which refers to you as either a Foster Care Parent or Foster Care Worker.

FOSTER CARE PARENT SECTION

14. What type of agency are you employed or licensed through?

1. County Department of Social Services
2. Private Child Placing Agency (please specify)_____
3. Both County Department of Social Servoces and Private.
4. Indian/Tribal
5. Other (please specify) _____

15. Total # of children presently in home_____

16. Number of foster female children_____

17. Number of foster male children_____

18. Circle age group of foster children:

1. all under 5
2. all under 10
3. all under 15
4. all under 18
5. all over 18
6. some under 18 & some over 18
7. no children now
8. not yet foster parents
9. other_____

19. Is at least one parent in the home providing parenting and supervision?

1. Yes 2. No, Parent(s) have work responsibilities outside of the home.

20. Length of involvement as foster family: _____years

21. Number of foster children for which licensed_____

22. Total number of foster children since being a foster parent_____

23. Circle general age groups of foster children you have served:

1. 0 - 24 mos.
2. 1 - 6 years
3. 0 - 12 years
4. 0 - 18 years
5. 0 - 21 years
6. short term/emergency

FOSTER CARE WORKER SECTION

24. What type of agency are you employed or licensed through?

1. County Department of Social Services
2. Private Child Placing Agency (please specify) _____
3. Indian/Tribal
4. Other _____ (please specify)

25. Are you currently employed as a foster care worker? 1. Yes 2. No

26. Length of time in current agency _____years

27. Current title:

1. Caseworker I
2. Caseworker II
3. Caseworker III
4. Supervisor I
5. Supervisor II
6. Foster Case Trainer
7. Other (specify) _____

28. Length of time in current position _____years

29. Length of time in protective services/foster care unit _____years